



ALBERTA RESOURCES

For individuals and families affected by
Primary Immunodeficiency (PI)



Immunodeficiency
Canada
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Canada

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by Primary Immunodeficiency (PI)

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Provincial Resources

Accommodation

Ronald McDonald House of Southern Alberta
111 West Campus Place NW
Calgary, Alberta T3B2R6
Telephone: 403-240-3000
<http://www.rmhsouthernalberta.org>

Dental

Recipients of Income Supports, Alberta Child Health Benefit or the Alberta Adult Health Benefit may receive coverage for extraordinary dental work. Their dentist needs to provide information to the applicable program which will then send a claim through the ADSC via a Health Benefits Exception request.

Financial Resources

Alberta Aids to Daily Living Program (A.A.D.L.)

This provides funding for some medical supplies and equipment and is available to all residents of Alberta. The cost share is A.A.D.L. 75% and the family 25%.

Edmonton: 780.427.0731, or toll free in Alberta: 310.0000, then 780.427.0731.

www.health.alberta.ca/services/aids-to-daily-living.html

Alberta Adult Health Benefit/ Alberta Child Health Benefit programs

Alberta Adult Health Benefit/ Alberta Child Health Benefit programs are designed to assist families meet daily needs. Qualifying families may receive support for items such as prescription drugs, eye glasses and diabetic supplies.

Edmonton 780.427.6848 or 1.877.469.5437 (toll free province wide).

<http://humanservices.alberta.ca/financial-support/2076.html>

Alberta Works Housing and Utility support

Alberta Works Housing and Utility support offers Albertans access to emergency accommodation, transportation, and meals when criteria are met.

Edmonton 780.644.5135 (24/7). Across Alberta 1.866.644.5135

www.humanservices.alberta.ca/financial-support/3171.html

Eye See...Eye Learn Program

This program was initiated by the Alberta Association of Optometrists. Children in Kindergarten are eligible to receive free glasses and frames. 1-855-424-ESEL (3735)

www.eyeseeeyelearn.ca

Family Support for Children with Disabilities (FSCD)

The FSCD program uses a family-centered approach to provide parents with funding to access a range of supports and services that strengthen their ability to promote their child's healthy growth and development. In addition, FSCD assists with some of the extraordinary costs of raising a child with a disability. Services are available to eligible children with disabilities and their families until the child turns 18 years old.

www.humanservices.alberta.ca/disability-services

Request for a Health Benefit Exception

Parents/guardians, who receive the Alberta Adult or Child Health Benefit and have a child that has been prescribed a medication that is not listed on the Health and Wellness Drug Benefit List, should refer to instructions pertaining to submitting a "Request for Drugs and Nutritional Products" form. Parents/guardians and the prescribing physician are required to complete forms that are sent for review by the Health Benefit Review Committee. Requests for Prescribed infant formula and special diet items may also be considered for funding using these forms.

Programs & Services

Alberta Association for Community Living, Family Voices Network - South Region

The Alberta Association for Community Living (AACL) developed networks of families, known as Family Voices, in each of six regions of the province to advocate regionally on behalf of children and adults with developmental disabilities. The Family Voices South Network can assist families from Region 1 CFSA in connecting with planning resources in their region.

Alberta Association for Community Living: 780.451.3055

Toll free within Alberta: 1.800.252.7556.

<http://www.aacl.org/family-voices/family-voices/>

Calgary Immigrant Aid Society

"Established in 1977 as the Calgary Immigrant Aid Society, for the past 30 years we have helped over 250,000 immigrants settle into their new life and home in Calgary, Alberta, Canada. As one of Calgary's most comprehensive immigrant serving agencies, our focus is on the individual and families first, providing a sense of community and connection".

910 7 Ave SW,

Calgary, AB T2P 3N8

Tel: (403) 265-1120

www.immigrantservicescalgary.ca

Children's Link Society

Children's Link Society is a family-centered, community-based, central access point of information for families of children with special needs in Calgary and Area. The Children's Link Society provides drop-in and phone support in walking through steps of transition.

Suite 245, 720 - 28th Street N.E, Calgary, Alberta T2A 6R3

Contact: 403-230-9158

www.childrenslink.ca

Jamie's Preschool

It provides a safer haven for immune-compromised children and their siblings. The program aims at keeping children who are immune-compromised, healthy, active, and engaged.

Unit 1, 3303 Capitol Hill Cres. NW Calgary AB T2M 2R2

Tel: 403-808-2296

www.jamiespreschool.ca

Pace Kids

Pace Kids is a family-focused program and strives to offer excellence in the treatment of children with special needs, emphasizing an intra-disciplinary direct treatment approach. This program is funded by Family Support for Children with Disability (FSCD).

#112 5211 MacLeod Trail S, Calgary, AB T2H 0J3

Tel: 403.234.7876

www.pacekids.ca

National Resources

Financial Resources

Canada Child Benefit (CCB)

This is a **tax-free** monthly payment made to eligible families to help them with the cost of raising children under 18 years of age. The CCB might include the [child disability benefit](#) and any related [provincial and territorial programs](#).

The Canada Revenue Agency uses information from your income tax and benefit return to calculate how much your CCB payments will be. To get the CCB, you have to file your return **every year, even if you did not have income in the year**. If you have a spouse or common-law partner, they also have to file a return every year.

Child disability benefit

If approved for the Disability Tax Credit, you are automatically assessed for this benefit. You do not need to apply. This benefit is based on family income, is tax-free, and paid monthly for low to moderate income families caring for a child under the age of 18 with a severe and prolonged impairment in mental or physical functions.

www.cra.gc.ca/cdb

Compassionate Care

Compassionate care benefits may be paid up to a maximum of 6 weeks to a person who has to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks. Unemployed persons on EI can also ask for this type of benefits. For more information and complete details: Toll-Free: 1 800 206-7218

Website: http://www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml

Disability Tax Credit

The Disability Tax Credit (DTC) is known as the “disability amount” on your income tax return. The DTC is a non-refundable credit that reduces the amount of income tax that a person with a disability, or their supporting person, might otherwise have to pay. The DTC is also used to determine eligibility for the Child Disability Benefit, an amount available under the Canada Child Tax Benefit for a child under 18 with a disability.

In order to claim the DTC, a person must file a completed Form T2201, Disability Tax Credit Certificate, signed by a qualified person. Forms are available at CRA offices, or by calling 1-800-959-2221; Form can also be downloaded from the CRA Website: www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html.

Employment Insurance Special Benefits for Parents of Critically Ill Children

You can receive Employment Insurance (EI) special benefits for Parents of Critically Ill Children (PCIC) for up to 35 weeks if you have to be absent from work to provide care or support to your critically ill or injured child. If you are unemployed and already receiving EI benefits, you can also apply for the PCIC benefit. To be eligible for the PCIC benefit, you must be able to show that: your regular weekly earnings from work have decreased by more than 40% because you need to provide care or support to your critically ill or injured child, you have accumulated 600 insured hours of work in the 52 weeks prior to the start of your claim, or since the start of your last claim, whichever is shorter (this period is called the qualifying period) you are the parent of a child who is critically ill or injured your child is under 18 years of age at the time the 52-week window during which PCIC benefits can be paid opens (based on the date the specialist medical doctor states that your child became critically ill or injured).

For more information, complete details, and forms:

<http://www.servicecanada.gc.ca/eng/sc/ei/pcic/index.shtml>

Family Caregiver Tax Credit

This is a tax credit that can be applied for when filing your current year tax return. The child must have a medical or physical infirmity and as a result of that infirmity is, and is likely to be for a long continued period of indefinite duration, dependent on others for significantly more assistance in attending to the child's personal needs and care when compared to children of the same age.

Website: <http://www.cra-arc.gc.ca/gncy/bdgt/2011/qa02-eng.html>

Medical Expenses Tax Credit

This applies to individuals who have significant medical expenses for themselves or their dependants. This is an income tax credit which is claimed when filing your current year tax return.

Website: www.cra.gc.ca

Programs & Services

Big Brothers and Big Sisters of Canada

Each Big Brother/Big Sister agency provides direct service to children by matching adults and children in quality mentoring relationships. Agency staff members are experts at screening

volunteers and matching them with a child having similar interests.

Website: www.bigbrothersbigsisters.ca

Cipo – Canadian Immunodeficiencies Patient Organization

CIPO is a volunteer based registered charity. CIPO has six regional Chapters in Canada that hold regular meetings and offer services to patients such as providing literature, advocacy, organizing educational events, and referrals.

<http://www.cipo.ca/>

Easter Seals Canada

Since 1922, Easter Seals has been leading the way to opportunities for Canadians with disabilities. Easter Seals operates as a network of provincially licensed members that deliver programs and services to Canadians with physical disabilities in their community.

Website: www.easterseals.ca

Immune Deficiency Foundation

This is a national non-profit health organization dedicated to improving the diagnosis and treatment of primary immune deficiency diseases through research and education. IDF is governed by a Board of Trustees, has an active Medical Advisory Committee comprised of prominent clinical immunologists, a nationwide volunteer support network, and a dedicated professional staff.

Website: www.primaryimmune.org/idf.htm

Jeffrey Modell Foundation - Friends of John for Life Kids Wish Fund

"Friends of John for Life Kids Wish Fund" is a special "set aside" fund by the Jeffrey Modell Foundation. The fund is designed simply to bring joy and happiness to the lives of kids with immune deficiencies. The fund sponsors tickets for sporting events, concerts, the theatre, days at the zoo, the circus and more. These funds are not for research, doctors, or administration.

Website: www.jmfworld.com/howtohelp/friends.cfm

Canada Medic Alert Foundation

Canada Medic Alert Foundation offers free medic alert bracelets to children across Canada.

No Child Without includes a free medical identification bracelet and electronic health record with 24/7 access so that critical health information is quickly available during a medical emergency. MedicAlert memberships are for students (from age 4 to their 14th birthday) in select schools. (www.nochildwithout.ca)

Membership Assistance Program ensures that any person with potentially life-threatening medical conditions can have access to services offered by MedicAlert, regardless of his/her ability to pay. <http://www.medicalert.ca/education/en/programs/assistance.asp>

The Children's Wish Foundation

Child may only have ONE wish either through Children's Wish, Make -a-Wish, or Starlight Foundation

The Children's Wish Foundation is a uniquely Canadian charity that helps Canadian children, families and communities grants wishes to children with high risk and life threatening illnesses.

Website: www.childrenswish.ca

Make-A-Wish Canada

Child may only have ONE wish either through Children's Wish, Make –a-Wish, or Starlight Foundation

The mission of Make-A-Wish® Canada is to grant the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength and joy.

Website: www.makeawish.ca

National Organization for Rare Disorders

This is a federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Website: www.rarediseases.org

Primary Immunodeficiency Resource Center

This website is designed to be a central resource on Primary Immunodeficiency. Its goal is to allow researchers, scientists, physicians, government, industry, patients and their families to be able to access this information quickly, efficiently, and seamlessly.

Website: <http://www.info4pi.org/>

Songs of Love

Songs of Love is a non-profit organization that provides personalized songs for children and young adults with a life threatening or chronic illness.

Website: www.songsoflove.org

Starlight Children's Foundation Canada

Child may only have ONE wish either through Children's Wish, Make –a-Wish, or Starlight Foundation

Starlight Children's Foundation is a non-profit organization dedicated to making a world of difference for seriously ill children and their families. Starlight offers an array of in-hospital, out-patient, school, and home-based programs and services that help to brighten the lives of children and families facing serious illnesses.

Website: www.starlightcanada.org

Young Minds Program – Children's Wish International

Young Minds is a wish program for children who have been diagnosed with a life-threatening illness and are under the age of three, or whose cognitive level is under the age of three. The child must NOT have had a wish fulfilled by another organization. A child is able to choose a package gift of a TV/DVD player, CD music collection, toys and dolls, comfort station with rocker, or activity assortment.

Website: www.childrenswish.org

Transportation

Air Canada Kids Horizon Program

This program provides free flights for children and a caregiver traveling anywhere in Canada for clinic appointments. Please contact your local children's hospital for availability. Families are responsible for taxes and fees.

Website: <http://www.aircanada.com/en/about/community/kids.html>

Hope Air

Hope Air (formerly Mission Air) is a national Canadian charity that arranges free air transportation for Canadians that need to travel to non-emergency medical care outside of their home communities and cannot afford the flight costs. To make a flight request or for more information call the bilingual staff Monday through Friday, 9:00 AM- 4:30 PM EST or visit them at their website.

Website: www.hopeair.org

Wigs

A Child's Voice – Angel Hair for Kids

Angel Hair for Kids provides wigs for eligible children who have hair loss due to chemotherapy, radiation, burns, or alopecia. This is a program through A Child's Voice Foundation.

Website: www.achildsvoicefoundation.com/AH-ABOUTUS.HTM

Wigs for Kids

This is a non-profit organization that provides hair replacement systems for eligible children 18 years or younger who have hair loss as a result of chemotherapy, alopecia, radiation treatments, burns, or other medical circumstances.

Website: www.wigsforkids.org

Immunodeficiency Canada

Emergency Financial Assistance

The Alastair Fund provides funding to families dealing with financial strain due to illness from a Primary Immunodeficiency. It is available to families with a child registered as a patient at: Alberta's Children's Hospital, British Columbia's Children's Hospital, Montreal's Children's Hospital and Toronto Hospital for Sick Children. Families can access financial assistance for transportation, overnight stays, food, parking and other critical needs. Families should talk to the Hospital Social Work Department to access this fund.

Publications

Immunodeficiency Canada strives to provide information that is relevant and up to date. Some materials are available in both English and French. Many materials are downloadable or print copies may be requested.

Website www.immunodeficiency.ca

Online Resources Guide for individuals and families affected by Primary Immunodeficiency

Individual Stories

Newsletters (current and past issues)

In print - What is Primary Immunodeficiency pamphlet?

10 Warning Signs for children and adults flyer

Social Media

Individuals are invited to join others affected by Primary Immunodeficiency and stay up to date through social media. Look for Immunodeficiency Canada on Facebook, LinkedIn, and the YouTube Channel.

Social Events

Immunodeficiency Canada sponsors and hosts events for families, adults, teens and children to help break the isolation many individuals and families feel and build networks of mutual support. Kids' picnics have been held in Montreal, Toronto and Calgary organized in partnership through local health care facilities. In the Greater Toronto Area, meet and greet evenings for adults and fun-filled events for teens are organized each year.

If you have comments or suggestions on *Resources for individuals and families affected by Primary Immunodeficiency* please forward them to contactus@immunodeficiency.ca

or mail to:

Immunodeficiency Canada

Suite 1604

415 Yonge Street

Toronto, Ontario M5B 2E7

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